Individual patient outcome measures recommended for use in older people’s mental health

Prepared by the Royal College of Psychiatrists’ Faculty of the Psychiatry of Old Age

October 2012
Individual patient outcome measures recommended for use in older people’s mental health

Prepared by the Royal College of Psychiatrists’ Faculty of the Psychiatry of Old Age

Occasional Paper OP86
October 2012

Royal College of Psychiatrists
London
© 2012 Royal College of Psychiatrists

Occasional Papers have not been formally approved by the Central Executive Committee of the Royal College of Psychiatrists and do not constitute College policy. Their distribution has been authorised by the College’s Officers with the aim of providing information or provoking discussion.

For full details of reports available and how to obtain them, contact the Book Sales Assistant at the Royal College of Psychiatrists, 17 Belgrave Square, London SW1X 8PG (tel. 020 7235 2351; fax 020 7245 1231) or visit the College website at http://www.rcpsych.ac.uk/publications/collegereports.aspx

The Royal College of Psychiatrists is a charity registered in England and Wales (228636) and in Scotland (SC038369).

**Disclaimer**

This guidance (as updated from time to time) is for use by members of the Royal College of Psychiatrists. It sets out guidance, principles and specific recommendations that, in the view of the College, should be followed by members. None the less, members remain responsible for regulating their own conduct in relation to the subject matter of the guidance. Accordingly, to the extent permitted by applicable law, the College excludes all liability of any kind arising as a consequence, directly or indirectly, of the member either following or failing to follow the guidance.
Working group

Lead

Dr Andy Barker

Members

Dr Pradeep Arya
Dr Paul Boston
Dr Waleed Fawzi
Dr Sean Lennon
Dr Nisha Mokashi
Dr Hugh Series
Professor Robert Stewart
Dr Jonathan Waite
Dr Graeme Yorston

Members of the Executive Committee of the Faculty of the Psychiatry of Old Age, Royal College of Psychiatrists.

Thanks also to Tom Dening and Sube Banerjee for their contributions.
Purpose of this document

The principal aim of this occasional paper is to provide a short guide for old age psychiatrists in the use of individual patient outcome measures, in the context of quality assessment and more global aspects of outcome measurement.

There is already substantial routine data collection in the National Health Service (NHS) for a range of purposes related to performance and quality. Our aim is not to suggest additions or alternatives to routinely collected data for benchmarking, nor to provide a mandated list of outcome measures for particular indications, but to recommend some measures that old age psychiatrists might find useful in practice for the improvement of care and assessment of individual patient outcomes.
What is quality?

Quality has been defined as incorporating three elements:

1. the effectiveness of the treatment and care provided to patients;
2. the safety of the treatment and care provided to patients; and
3. the broader experience patients and their carers have of the treatment and care they receive (Department of Health, 2008).

Quality was highlighted as central to the future of the NHS in the 2008 NHS next stage review *High Quality Care For All*:

’an NHS that gives patients and the public more information and choice works in partnership and has quality of care at its heart’. (Department of Health, 2008: p. 8)

More recently, the present government’s strategy *Equity and Excellence: Liberating the NHS*, continued this theme:

‘Building on Lord Darzi’s work, the Government will now establish improvement in quality and healthcare outcomes as the primary purpose of all NHS-funded care.’ (Department of Health, 2010: p. 21)
How should quality be measured?

Quality is commonly measured in terms of structure, process and outcome.

- **Structure** – what resources are available and how should they be structured to maximise good patient outcomes?
- **Process** – what should be done to maximise good outcome for the patient?
- **Outcome** – what actually happens to the health of the patient?

Structural measurement might be seen as an assessment of the building blocks of a service. What staff, buildings and equipment are required for good-quality care, and how should they be organised? Structural measurement does not tell you about the quality of activity that is being carried out by these resources.

Process measurement is based on the hypothesis that there are interventions (processes) that have been shown to be associated with better quality of care. If a service can assure itself that these interventions are being carried out, then it can conclude that good care is being delivered. Much guidance, such as that produced by the National Institute for Health and Clinical Excellence (NICE) and the Royal College of Psychiatrists’ accreditation schemes is based on a well-established evidence base, and includes assessment and audit tools to demonstrate compliance at service level.

Outcome measurement takes the position that irrespective of what structures are in place, or what processes are being carried out, the only true way of seeing whether services are effective is to look at the effect on the service user. Outcome measures may be used to judge service quality, but are of wider importance in improvement activities such as reflective practice and audit. Ultimately, outcome measurement is the most valid determination of the benefit to the patient from care interventions, but process measures as described here will need to be maintained until robust and reliable outcome measures can be incorporated into routine practice in a cost-effective way.
The government has published an outcomes framework for mental health (HM Government, 2011) including proposed indicators for measuring the mental health of the general population. This makes links with the NHS outcomes framework, and the public health and adult social care outcomes frameworks. The mental health outcomes framework identifies a number of other possible indicators for national and local use, discusses where process indicators may need to be superseded, and highlights the NICE quality standards in development (including dementia and depression). These are likely to be included in the commissioning outcomes framework being developed by NICE on behalf of the NHS Commissioning Board.

The mental health Payment by Results programme is also likely to introduce outcome indicators based on routinely collected data for mental health service users within clusters. Likely indicators include Mental Health Recovery Star, Carers’ and Users’ Expectations of Services (CUES), 9-item Patient Health Questionnaire – depression severity index (PHQ-9), 7-item Generalised Anxiety Disorder scale (GAD-7), Patient Reported Outcome Measures (PROMs), Patient Reported Experience Measures (PREMs), Health of the Nation Outcome Scales (HoNOS) and some specific clustering tool items. A core measure, HoNOS is embedded within the clustering assessment and therefore will be routinely collected. One possibility would be to use HoNOS to target specific assessments where need is rated as moderately severe or severe.

At the level of the individual patient, a number of compendia of outcome measures for psychiatry are available, including one facilitated by the Department of Health that describes measures according to their quality (National Institute for Mental Health in England, 2008). This occasional paper draws upon that work.

Mental health is not only measured by symptoms and diagnoses, but by quality of life, social functioning and social inclusion, and self-reported well-being. These have been promoted by service users because they are felt to enhance optimism and a sense of personal control.

In developing the shortlist of outcome measures presented in the next chapter, we have borne in mind their evidence base and reliability/validity in older adult populations, their practicality (are they free, easily available, brief, do they require training), and their user-friendliness to staff and service users. The list is not exhaustive and individual clinicians with specific needs may well want to select other measures.
Summary of recommended measures

The outcome measures selected here are discussed in more detail in the Appendix.

The HoNOS tool has been accepted as part of the Mental Health Minimum Data Set (MHMDS). It is the basis of payment by results clustering and therefore will be routinely collected. Its sensitivity will vary with the quality and training of raters. A specific version of the HoNOS was developed for use in older adults (HoNOS65+). At the time of writing, it is unclear whether it will be possible to incorporate the HoNOS65+ version into the clustering methodology for routine use. One possibility would be to use this global measure and then consider specific measures for domains where need is rated as moderately severe or severe (3 and 4).

Table 1 Outcome measures recommended in old age psychiatry – summary

<table>
<thead>
<tr>
<th>Domain</th>
<th>Outcome measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Global measures</td>
<td>• Health of the Nation Outcome Scales (HoNOS) and HoNOS for older adults (HoNOS65+)</td>
</tr>
<tr>
<td></td>
<td>• Functional Assessment of the Care Environment (FACE)</td>
</tr>
<tr>
<td>2 Cognition</td>
<td>• Mini-Mental State Examination (MMSE)</td>
</tr>
<tr>
<td></td>
<td>• Montreal Cognitive Assessment (MoCA)</td>
</tr>
<tr>
<td></td>
<td>• Addenbrooke’s Cognitive Examination Revised (ACE-R)</td>
</tr>
<tr>
<td>3 Delirium</td>
<td>• short Confusion Assessment Method (short-CAM)</td>
</tr>
<tr>
<td></td>
<td>• Delirium Rating Scale (DRS)</td>
</tr>
<tr>
<td>4 Depression</td>
<td>• Geriatric Depression Scale (GDS)</td>
</tr>
<tr>
<td></td>
<td>• Hospital Anxiety and Depression Scale (HADS)</td>
</tr>
<tr>
<td></td>
<td>• Patient Health Questionnaire – depression severity index (PHQ-9)</td>
</tr>
<tr>
<td></td>
<td>• Cornell Scale for Depression in Dementia (CSDD)</td>
</tr>
<tr>
<td>5 Anxiety</td>
<td>• Patient Health Questionnaire – Generalised Anxiety Disorder severity index (GAD-7)</td>
</tr>
<tr>
<td></td>
<td>• HADS</td>
</tr>
<tr>
<td>6 Psychological therapies</td>
<td>• Clinical Outcomes Review Evaluation (CORE 10)</td>
</tr>
<tr>
<td></td>
<td>• Outcome Rating Scale (ORS)</td>
</tr>
<tr>
<td>7 Psychosis</td>
<td>• Brief Psychiatric Rating Scale (BPRS)</td>
</tr>
<tr>
<td></td>
<td>• Positive and Negative Syndrome Scale (PANSS)</td>
</tr>
<tr>
<td>8 Activities of daily living</td>
<td>• Bristol Activities of Daily Living scale (BADL)</td>
</tr>
<tr>
<td></td>
<td>• World Health Organization Short Disability Assessment Schedule (WHODAS-S)</td>
</tr>
<tr>
<td>9 Quality of life</td>
<td>Non-dementia:</td>
</tr>
<tr>
<td></td>
<td>• Short Form Health Survey (SF-12)</td>
</tr>
<tr>
<td></td>
<td>• EuroQol</td>
</tr>
<tr>
<td></td>
<td>• Dementia:</td>
</tr>
<tr>
<td></td>
<td>• DEMQOL</td>
</tr>
<tr>
<td></td>
<td>• Quality of Life in Alzheimer’s Disease (QoL-AD)</td>
</tr>
</tbody>
</table>
| 10 Carer's outcome | Zarit Burden Interview  
|                   | Carers’ and Users’ Expectations of Services – Carer Version (CUES-C) |
| 11 Service satisfaction | Client Satisfaction Questionnaire  
|                        | Patient Experience Questionnaire (PEQ) (Part 2) |
| 12 Recovery and well-being | Mental Health Recovery Star  
|                           | Life Satisfaction Index |
| 13 Behaviour that challenges | Cohen-Mansfield Agitation Inventory (CMAI)  
|                               | Neuropsychiatric Inventory (NPI) |
Conclusions

Although individual outcome measurement is the best way to measure the quality of care and gives clinicians accurate data from which to reflect on their practice, there are some additional factors that should be taken into consideration when introducing routine outcome measurement.

- Routine standardised assessments can be time intensive and laborious for staff to complete, with unclear cost–benefit ratio. Care should be taken in considering the exact purpose for which data are being collected and selecting the appropriate measure to fit this. Where possible, existing routine data collections should be used to inform on service quality and patient outcome. Pilot well before introducing new routine data collection.

- Attempts to improve quality will require existing process measures (e.g. adherence to guidelines) until such time as routine individual patient outcome measurement is cost-effective.

- If one intention of the outcome measurement is to compare services or clinicians, then: standardised measures are required; reliable and valid assessments need to be performed; all services/clinicians need to use the same measure for the same indication; and any comparisons need to take account of differences in case-mix and resource level.

- Outcome measures should include outcomes that are important to patients and carers, such as quality of life and well-being, and not be purely symptom based.

- An information infrastructure is required to routinely collate and feed back results to clinicians; IT support should simplify the data collection and analysis, and ensure maximum use of data collected. Data should be checked for reliability. There should be timely feedback of the data to patients, carers and clinicians so it can influence the treatment process.
Appendix

Outcome measures recommended in old age psychiatry.
### Table 1A  Outcome measures recommended in old age psychiatry

<table>
<thead>
<tr>
<th>Tool</th>
<th>What it measures</th>
<th>Availability</th>
<th>Practicalities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 Global measures</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Health of the Nation Outcome Scales (HoNOS)  
HoNOS for Older Adults (HoNOS65+) (Wing, 1994) | Intended to measure outcome and need, and inform the provision of healthcare at a population level  
In 1993, the UK Department of Health commissioned the Royal College of Psychiatrists’ Research Unit (CRU) to develop scales to measure the health and social functioning of people with severe mental illness. The initial aim was to provide a means of recording progress towards the Health of the Nation target ‘to improve significantly the health and social functioning of mentally ill people’ | Training is required plus training costs  
Freely available to National Health Service and non-profit organisations  
Copyright in HoNOS is owned by the Royal College of Psychiatrists (further information and downloads: www.rcpsych.ac.uk/training/honos.aspx) | Practitioner-completed over time  
≥20 min to complete  
5 min following assessment |
| Functional Assessment of the Care Environment (FACE) | Assessment and care planning tools for health and social care. Multidimensional measure of:  
psychological well-being  
activities of daily living  
physical well-being  
interpersonal relationships  
social circumstances  
impact on carers  
risk.  
The FACE tools support the mental health minimum data-set and generate a HoNOS score  
Assessment and outcome measurement tools available for older people’s mental health services | Training required  
Several toolkits available  
Requires copyright permission  
Use of the Assessment and Outcome Package is free except for the software, but the clinician, team or organisation must register with CORE (www.coreims.co.uk)  
Further information from FACE Recording and Measurement Systems (www.face.eu.com) | FACE Outcomes Software provides continual feedback to maintain data quality and provide real-time benchmarking |
| **2 Cognition** | | | |
| Mini-Mental State Examination (MMSE) | The most widely used cognitive screening tool for dementia in secondary care  
Also recommended by the National Institute for Health and Clinical Excellence (NICE) for outcome measurement and staging of dementia severity  
Insensitive to change, affected by education and does not assess frontal executive functions | Currently free and easily available, although it is copyrighted, and at time of writing the possibility of charging was being discussed | Requires little training, completed in <10 min |
### Montreal Cognitive Assessment (MoCA)
- The MoCA tool is also a screening test for dementia, well validated with normative data, although benefits from having questions that assess frontal executive function.
- If charges for the MMSE were to be introduced, this may shift preference towards the MoCA.

- Copyrighted but free to use and available to download (www.mocatest.org).
- Requires little training, completed in <10min.

### Addenbrooke’s Cognitive Examination Revised (ACE-R) (Mioshi et al, 2006)
- A more detailed and lengthier cognitive screening test for dementia which claims higher sensitivity and specificity than the MMSE.
- Covers domains of orientation/attention, memory, verbal fluency, language and visuospatial, helpfully providing frontal executive functioning and more detailed memory testing, which are both advantages over the MMSE.

- Copyrighted but freely available on the internet.
- The Administration and Scoring Guide 2006, which is also copyrighted but freely available on the internet, suggests the test takes about 15min.

### 3 Delirium

#### Confusion Assessment Method (CAM) Inouye et al (1990)
- Intended to aid screening for delirium in inpatient settings.
- Consists of two sections: a checklist for 11 features of cognitive impairment suggestive of delirium; and a list of four features (with advice on their ascertainment) found to be most discriminative for delirium against other causes of cognitive impairment (the short form): (1) acute onset or fluctuating course; (2) inattention; (3) disorganised thinking; (4) altered level of consciousness. Diagnostic criteria are the presence of both features 1 and 2 and either 3 or 4.

- Widely available on the internet, but uncertain copyright status.
- Easy and quick to administer, but understandably is designed to be completed following a period of observation and taking into account both the mental state and the recent course of the cognitive disturbance.
- Extensive validation against clinical assessments and other cognitive outcomes.

#### Delirium Rating Scale (DRS)
- In contrast to the CAM, the DRS was developed as an instrument to measure severity of delirium symptoms rather than simply their presence. The original version asks about 10 features, with 0–3 or 0–4 point ratings for each one, generating a summary score when totalled.

- As with the CAM, easy and quick to administer but based on a period of observation rather than a one-off assessment.
- Designed to be repeated for quantifying course.
- Some deficiencies were highlighted resulting in a revised version (DRS-98-R).
### Delirium Rating Scale-Revised-98 (DRS-98-R)
- Designed to improve the DRS for longitudinal (i.e. repeated) application
- Among other limitations, three of the original DRS items (temporal onset, fluctuation and physical aetiology) had been included to assist with differential diagnosis, but were not helpfully repeated in serial administration. Also, the original DRS combined psychomotor hypo- and hyperactivity
- The revised version contains 11 features to be rated, all with 0–3 point levels
- Originally published with a full tabulation of the instrument and instructions in Trzepacz et al (2001)
- An improvement on the original scale both in terms of its face validity and in the visual appeal of the rating scale
- The same issues apply regarding the need for prior observation/records/information

### 4 Depression

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Description</th>
<th>Permission Required</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geriatric Depression Scale (GDS)</td>
<td>30-item, 15-item (Short Form), 10-item (Yesavage et al, 1983)</td>
<td>Yes</td>
<td>Both self- and practitioner-completed</td>
</tr>
<tr>
<td></td>
<td>May be used with healthy, medically ill and mild to moderately cognitively impaired older adults</td>
<td></td>
<td>5–7 min to complete</td>
</tr>
<tr>
<td></td>
<td>Has been extensively used in community, acute and long-term care settings</td>
<td></td>
<td>The Short Form is more easily used by people with mild to moderate dementia who have a short attention span and/ or feel easily fatigued</td>
</tr>
<tr>
<td></td>
<td>Useful screening tool in the clinical setting to facilitate assessment of, and monitor depression in, older adults over time in all clinical settings</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Does not assess suicide (any positive score above 5 on the GDS Short Form should prompt an in-depth psychological assessment and evaluation for suicide)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Shorter forms are available including a 15-item and 10-item scale, although the shorter versions may be less likely to be sensitive to change as an outcome measure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital Anxiety and Depression Scale (HADS) (Zigmond &amp; Snaith, 1983)</td>
<td>To detect states of anxiety and depression</td>
<td>Yes</td>
<td>Training not required</td>
</tr>
<tr>
<td></td>
<td>Primary care screening</td>
<td></td>
<td>Self-completed</td>
</tr>
<tr>
<td></td>
<td>Used in population of malignant disease and most medical populations</td>
<td></td>
<td>≤10 min to complete</td>
</tr>
<tr>
<td></td>
<td>Specifically designed for use in people with physical illnesses, focusing on non-somatic symptoms of depression/anxiety (and therefore may miss some syndromes with predominantly somatic symptoms)</td>
<td></td>
<td>Easy to score</td>
</tr>
<tr>
<td></td>
<td>Commercial use requires copyright permission or purchase of the questionnaires, both of which must be obtained from GL Assessment (<a href="http://www.gl-assessment.co.uk">www.gl-assessment.co.uk</a>)</td>
<td></td>
<td>No software required</td>
</tr>
</tbody>
</table>

Permission is granted to reproduce, post, download and/or distribute, provided that The Hartford Institute for Geriatric Nursing, College of Nursing, New York University, is cited as the source.
### Patient Health Questionnaire – depression severity index (PHQ-9) (Spitzer et al., 1999)
- Diagnostic tool of depression as well as severity measure
- Part of the Improving Access to Psychological Therapies (IAPT) suite of outcome measures. Like GAD-7, the PHQ-9 is the depression module/subscale derived from the 60-item Patient Health Questionnaire (PHQ; a self-administered version of the PRIME-MD diagnostic instrument for common mental disorders)
- Diagnostic monitoring system used to measure depressive symptoms across all medical areas
- Free to use under licence from Pfizer (www.phqscreensers.com)
- PHQ-9 copyrighted
- Self-completed
- ≤20 min to complete
- Easy to score and interpret hand-scored
- Training not required

### Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos et al., 1988)
- Developed for the assessment and diagnosis of depression in dementia, avoiding the necessity for patient-provided information
- Combination of observed and informant-based items
- Freely available online (e.g. on the Australian Department of Health and Ageing website: www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-rescare-natframe.htm~ageing-rescare-natframe08.htm)
- 20 min with carer, 10 min with patient

### 5 Anxiety

### Patient Health Questionnaire – Generalised Anxiety Disorder severity index (GAD-7) (Spitzer et al., 1999)
- Part of the IAPT suite of outcome measures tested in primary care sample
- A reliable brief scale to identify general anxiety disorder and measure the severity of its symptoms
- 7-item anxiety module/subscale derived from the 60-item PHQ
- Available for use free of charge under licence from Pfizer (www.phqscreensers.com)
- GAD-7 copyrighted
- Self-completed
- ≤20 min to complete
- No software required
- Easy to score

### Hospital Anxiety and Depression Scale (HADS)
See under Depression

### 6 Psychological therapies

### Clinical Outcomes Routine Evaluation (CORE)
- CORE was designed to provide a routine outcome measuring system for psychological therapies and some areas of psychiatry
- Also measures individual differences on entry into therapy and change
- Brief, covers well-being, problems/symptoms, life functioning and risk to self and others
- CORE-10 is brief and screens for severity and risk
- Training required
- Copyrighted by the authors, but can be downloaded for free (www.coreims.co.uk)
- User should contact CORE Systems if the tools are to be incorporated into existing service database systems, in which case a licence fee may be charged
- Both self- and practitioner-completed
- 15–30 min to complete
- CORE Systems provide optional software and training/consultancy at an additional charge through CORE-PC and CORE-NET
| **Outcome Rating Scale (ORS)**  
| (Miller et al, 2003) | - Measuring change for a variety of therapeutic models and identifying clients at risk or null outcomes for therapy | - Free, not copyrighted, available on the internet | - Self-completed  
| | | - <2 min to complete  
| | | - Easy to score and interpret  
| | | - Training not required |

### 7 Psychosis

| **Brief Psychiatric Rating Scale (BPRS)**  
| (Overall & Gorham, 1962) | - A rapid assessment of global psychiatric symptomatology particularly suited to the evaluation of patient change  
| | - An 18-item scale measuring positive symptoms, general psychopathology and affective symptoms. Some items are based on observation and some on verbal self-report by the patient | - Freely available on the internet  
| | | - No apparent copyright issues | - Time taken = 18 min by trained interviewer, 2–3 min after clinical assessment |

| **Positive and Negative Syndrome Scale (PANSS)**  
| Related assessment/tools: PANSS is a development from the BPRS  
| (Kay et al, 1987; Kay, 1991) | - PANSS is a 30-item rating instrument evaluating the presence/absence and severity of positive, negative and general psychopathology of schizophrenia and related disorders  
| | - Developed from the BPRS and the Psychopathology Rating Scale  
| | - Drug-sensitive instrument | - Personnel trained in psychiatric interview techniques, with experience working with populations with schizophrenia (e.g. psychiatrists, mental healthcare professionals)  
| | | Copyrighted (www.mhs.com/product.aspx?gr=cli&id=overview&prod=panss) | - Practitioner/observer completed  
| | | - 30–40 min to complete  
| | | - Hand-scored  
| | | - Software not required  
| | | - All 30 items are rated on a 7-point scale (1, absent; 7, extreme) |

### 8 Activities of daily living

| **Bristol Activities of Daily Living Scale (BADL)**  
| (Bucks et al, 1996) | - Assessment of activities of daily living in patients with dementia in the community  
| | - Specifically designed for use in people with dementia, covers 20 daily living activities  
| | - Tested for validity and reliability | - Freely available online  
| | | - Self-completed  
| | | - ≤5 min to complete  
| | | - 12-item versions: ≤5 min to complete  
| | | - 36-item versions: ≤20 min to complete  
| | | - Training manual available |

| **World Health Organization Short Disability Assessment Schedule (WHODAS-S)** | - Designed for clinician’s assessment and rating of adults with difficulties due to mental disorders, the WHODAS-S can be used for measuring the level of disability across various conditions and interventions  
| | - Includes six domains: understanding and communicating; getting around; self-care; getting along with others; household and work activities; and participation in society  
| | - Tested for reliability and validity in a number of areas of psychiatry and found to be clinically useful, including in people with dementia  
| | - The 36-item, 6-domain version has excellent psychometric properties, although a 12-item version is also available as a self-administered or interviewer-based tool | - Versions of the WHODAS II are available free with permission through the WHO (fully structured self-administered version, interviewer-administered version, proxy version; each comes in a short- and long-item variety)  
| | | A semi-structured questionnaire is being developed. It can be downloaded from (www.who.int/icidh/whodas/index.html) | - Self-completed  
| | | - 12-item versions: ≤5 min to complete  
| | | - 36-item versions: ≤20 min to complete  
| | | - Training manual available |
### 9 Quality of life

**Non-dementia**

<table>
<thead>
<tr>
<th><strong>Short Form Health Survey 36 (SF-36)</strong></th>
<th><strong>EuroQol 5-dimensions (EQ-5D)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Related assessment tools:</strong> SF-20, SF-12 (Brazier et al, 1992; Ware et al, 1996)</td>
<td><strong>Standardised instrument for use as a generic measure of health outcome, for all areas of health, conditions and for treatment effects</strong></td>
</tr>
<tr>
<td><strong>Generic</strong></td>
<td><strong>Provides a simple descriptive profile and a single index value for health status and clinical utility</strong></td>
</tr>
<tr>
<td><strong>Quality of life</strong></td>
<td><strong>3-level and 5-level versions are available, the 5-level one designed to further improve the sensitivity and reduce ceiling effects of the 3-level version</strong></td>
</tr>
<tr>
<td><strong>Multipurpose short measure of quality of life developed through the Medical Outcomes Study (<a href="http://www.rand.org">www.rand.org</a>)</strong></td>
<td><strong>Information about this instrument can be found on the EuroQol website (<a href="http://www.euroqol.org">www.euroqol.org</a>)</strong></td>
</tr>
<tr>
<td><strong>Contains 36 items, assesses general health status and can be used to demonstrate outcomes</strong></td>
<td><strong>It is in the public domain and may be used freely except in instances of commercial use</strong></td>
</tr>
<tr>
<td><strong>Focuses on eight health concepts: physical function; role limitations due to physical health problems; pain; general health; vitality (energy and fatigue); social function; role limitations due to emotional problems; and mental health (psychological distress and well-being)</strong></td>
<td><strong>Copyrighted</strong></td>
</tr>
<tr>
<td><strong>Designed for use in clinical practice, health policy evaluations and general population surveys. Suitable for all areas primary care community</strong></td>
<td><strong>Historically, following registration, consent will be given for free academic and clinical use of the EQ-5D</strong></td>
</tr>
<tr>
<td><strong>The short form (SF-12) is considered by users to provide good performance, with the longer version adding little practical benefit in routine use</strong></td>
<td><strong>Licensing fees are determined by the EuroQol Executive Office and dependent upon the type of study/trial/project, funding source, sample size and number of requested languages</strong></td>
</tr>
</tbody>
</table>

**Copyrighted**

- The original SF-36 is available through a public domain licence, free, from RAND Health (www.rand.org). Other versions require a purchased licence (www.sf-36.org)

**Self-completed**

- ≤20 min to complete
- Computer-assisted packages available for scoring if required
- Training not required

**Self-completed**

- ≤5 min to complete
- Primarily designed for self-completion in paper format by the patient or respondent, EQ-5D data can also be collected using a variety of alternative modes of administration
### Dementia

**DEMQOL**
- Specifically designed to measure health-related quality of life of people with dementia
- Designed to work across dementia subtypes and care settings
- Can be used at all stages of dementia
- Freely available through the King’s College London website (www.kcl.ac.uk/iop/depts/hsp/r/research/cemh/mha/demqol/index.aspx)
- Training recommended
- Consists of 2 questionnaires: a 28-item interviewer-administered questionnaire answered by the person with dementia; and the DEMQOL-proxy, a 31-item interviewer-administered questionnaire answered by a caregiver

**Quality of Life in Alzheimer’s Disease (QoL-AD)**
- Designed to rate a patient’s quality of life from the perspective of the patient and caregiver
- Includes assessments of the individual’s relationships, concerns about finances, physical condition, mood and an overall assessment of life quality
- Tested for validity and reliability
- Used in mild, moderate and severe dementia
- Copyrighted, but freely available (e.g. www.dementia-assessment.com.au/quality/QOL_handout_guidelines_scale.pdf)
- Brief 13-item measure
- Each item is rated on a 4-point scale
- The questionnaire takes caregivers 5 min and an interview of the patient 10–15 min (although this could be included in a routine clinical interview)

### 10 Carer’s outcomes

**Zarit Burden Interview** (Parks & Novielli, 2000)
- Widely referenced in studies of caregiver burden
- Comprises a 22-item scale (5 points per item)
- A 12-item and 4-item version (short and screening) are available and seem to have similar properties to the full version
- Appropriate for use with a variety of populations
- Scores are significantly positively correlated with behavioural problems in older adult patients and depression scores of caregivers
- Copyrighted, but freely available on the internet (www.aafp.org/afp/2000/1215/p2613.html)
- Caregiver self-report measure
- No training required

**Carers’ and Users’ Expectations of Services – Carer’s Version (CUES-C)** (Lelliott et al, 2003)
- Developed as a brief instrument to identify and measure the experience of those caring for people with a severe mental illness (including dementia) across the range of domains that the carers themselves consider important, including the impact of caring and the quality of support provided for carers
- Ideally, should be used to improve communication in the context of individual care planning
- May be better for needs assessment than as an outcome measure
- Copyrighted: ©Royal College of Psychiatrists (contact: Enquiries@cru.rcpsych.ac.uk)
- Self-completed, 13-item questionnaire
### 11 Service satisfaction
(The Care Quality Commission has used outcome measures for patient and carer experience as part of their in-patient and community mental health service surveys, although these have not been validated.)

<table>
<thead>
<tr>
<th>Client Satisfaction Questionnaire (CSQ)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ All areas of mental health</td>
<td>▪ Copyrighted. Permission required from Dr C.C. Attkisson (CSQ-8) at the UCSF Graduate Division, 200 West Milberry Union, 513 Parnassus Avenue, San Francisco, California, USA</td>
</tr>
<tr>
<td>▪ To measure satisfaction with health and health services received by individuals and families</td>
<td>▪ Self-completed</td>
</tr>
<tr>
<td>▪ Adult, adolescent and paediatric patients</td>
<td>▪ ≤20 min to complete, less for shorter versions</td>
</tr>
<tr>
<td>▪ Generic</td>
<td>▪ Can be scored and simply analysed using routinely available software</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient Experience Questionnaire (PEQ) Part 2</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Developed specifically for the Department of Health IAPT programme</td>
<td>▪ Free, can be downloaded from: <a href="http://www.iapt.nhs.uk/services/measuring-outcomes">www.iapt.nhs.uk/services/measuring-outcomes</a></td>
</tr>
<tr>
<td>▪ A measure of satisfaction and assessing the quality of patient experience. Helps to determine quality, efficiencies and the effectiveness of services provided</td>
<td>▪ Self-completed</td>
</tr>
<tr>
<td>▪ Enables service providers to appropriately redesign services so that they may have an equal place in the market of contestability</td>
<td>▪ Easy to score and interpret</td>
</tr>
<tr>
<td>▪ Administered once at around the end of that step of care, either before the end of treatment or in the final session</td>
<td>▪ Training not required</td>
</tr>
</tbody>
</table>

### 12 Recovery and well-being

<table>
<thead>
<tr>
<th>Mental Health Recovery Star</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Helping recovery from mental illness. Recovery means a satisfying, hopeful and contributing life even with the limitations caused by illness. It involves the development of a new meaning and purpose beyond the effect of mental illness</td>
<td>▪ Copyrighted: permission required</td>
</tr>
<tr>
<td>▪ Making changes, and understanding change in relation to different stages. Patients find it helps to think about which stage they are in and to get a picture of where they are on their journey</td>
<td>▪ Free download for non-profit organisations</td>
</tr>
<tr>
<td>▪ Looks at ten dimensions of life: managing mental health; relationships; self-care; addictive behaviour; living skills; responsibilities; social networks; identity and self-esteem; work; trust and hope.</td>
<td>▪ Training required</td>
</tr>
<tr>
<td>▪ Mental Health Recovery Star is an official version of the Outcomes Star, a suite of tools developed by Triangle Consulting for measuring outcomes in social care (<a href="http://www.outcomesstar.org.uk">www.outcomesstar.org.uk</a>)</td>
<td>▪ Mental Health Recovery Star is an official version of the Outcomes Star, a suite of tools developed by Triangle Consulting for measuring outcomes in social care (<a href="http://www.outcomesstar.org.uk">www.outcomesstar.org.uk</a>)</td>
</tr>
</tbody>
</table>

- Copyrighted: permission required
- Free download for non-profit organisations
- Training required
- Mental Health Recovery Star is an official version of the Outcomes Star, a suite of tools developed by Triangle Consulting for measuring outcomes in social care (www.outcomesstar.org.uk)
- Self-completed
- >20 min to complete
- Scoring not applicable
- Assessment
- No software required
## Life Satisfaction Index
(Neugarten et al, 1961)
- A measure of general well-being or morale in older people
- Designed to measure satisfaction or ‘successful’ ageing
- Comprises 20 statements, of which 12 are positive and 8 are negative; the client either agrees or disagrees with the statements (each with a score of 0–2)
- Older adults
- Freely available online and at Neugarten et al, 1961 (includes copy of the assessment)
- Self-completed
- ≤20 min to complete
- Easy to score and interpret
- Training not required

### 13 Behaviour that challenges

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Description</th>
<th>Availability</th>
<th>Time</th>
<th>Training Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cohen-Mansfield Agitation Inventory (CMAI)</td>
<td>Assesses 29 different agitated behaviours in people with cognitive impairment, including wandering, aggression, inappropriate vocalisation, hoarding items, sexual disinhibition and negativism</td>
<td>Freely available (e.g. <a href="http://www.dementia-assessment.com.au/symptoms">www.dementia-assessment.com.au/symptoms</a>)</td>
<td>Takes 10–15 min and can be carried out by carers</td>
<td>Takes 10 min to administer and assess</td>
</tr>
<tr>
<td>(Cohen-Mansfield et al, 1989)</td>
<td>Usefulness for the assessment of agitation in residents of nursing and residential homes</td>
<td>Copyrighted by the Gerontological Society of America</td>
<td>The items are rated on a 7-point scale of frequency</td>
<td>Clinician interview of carer</td>
</tr>
<tr>
<td>Neuropsychiatric Inventory (NPI)</td>
<td>Ten domains of psychopathology evaluated: delusions, hallucinations, dysphoria, anxiety, agitation/aggression, euphoria, disinhibition, irritability/lability, apathy, and aberrant motor behaviour</td>
<td>Freely available (<a href="http://npitest.net">http://npitest.net</a>)</td>
<td>Takes 10 min to administer and assess</td>
<td>All NPI case report forms must carry copyright notification</td>
</tr>
<tr>
<td>(Cummings et al, 1994)</td>
<td>Severity and frequency are independently assessed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A screening strategy cuts down the administration time</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a. Another tool that is widely used in practice, although not recommended here, is Barthel Activities of Daily Living Index (Mahoney & Barthel, 1965). The Barthel Index provides an assessment of physical disability for older people. It is probably the oldest and most widely used scale to assess physical disability and has been thoroughly tested for validity, reliability, sensitivity and clinical utility. Explicit guidelines for rating have been suggested, as well as an amended scoring system. It is brief, taking only 5 min, rated by an informant or in consultation with an informant, and covers 10 areas to be rated as needing help or independent. However, although it may be useful for needs assessment, clinicians report it not sensitive to change in routine clinical practice, so it cannot be recommended for routine outcome measurement.


Individual patient outcome measures recommended for use in older people’s mental health

Prepared by the Royal College of Psychiatrists’ Faculty of the Psychiatry of Old Age

October 2012